

Advanced Directive/Do Not Resuscitate Information Packet

Statement: The Department supports the right of individuals who receive services through the Division of MR/DD to obtain, refuse, or discontinue life sustaining treatment in the event of terminal illness. This informational packet is intended to provide individuals, families, guardians, and advocates relevant information when exploring life sustaining treatment decisions.

Medical and Legal Terms:

Cardiopulmonary Resuscitation (CPR) includes cardiac compression, artificial ventilation and oropharyngeal airway (OPA) insertion, advanced airway management such as endotracheal intubation, cardiac resuscitation drugs, defibrillation and related procedures.

Do Not Resuscitate (DNR) Orders a medical order written by a physician to withhold CPR including breathing/ventilation by an assistive or mechanical means including but not limited to, mouth-to-mouth, mouth-to mask, bag-valve mask, endotracheal tube, ventilator and/or chest compressions, and/or defibrillation. This order can not be written without the informed consent of a competent individual or if an individual is not competent, their duly authorized healthcare agency or their guardian. The order is placed in the consumer's medical record and indicates intent to withhold cardiopulmonary resuscitation (CPR) in the event the individual experiences a respiratory or cardiac arrest.

Durable power of attorney for health care: a written instrument executed by a competent adult, notarized and expressly giving an agent or attorney-in-fact the authority to consent to or to prohibit any type of health care, medical care, treatment or procedures.

Duly Authorized Health Care Agent: legally responsible individual responsible for making medical decisions for specified individual.

Terminal condition: an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures (RSMO 459.010). "Short time" is defined by MO Division of MRDD as 6 months or less.

Advance Directives: a written instrument, such as a living will or durable power of attorney for health care, relating to the provision of health care for an individual when that individual is in a terminal condition or is incapacitated. 9 CSR 10-5.180 1(B)

General Information and Questions related to life sustaining treatment decisions:

Why obtain Advance Directives?

You accomplish at least two things by obtaining advance directives, regardless of whether they direct all possible treatment, no treatment or only some treatment. First, you ensure that the treatment you receive is the treatment you desire, no more and no less. Second, you take the burden off of your family and friends to make those decisions for you at a time when they will most likely be emotionally upset by your critical condition. Finally, you may be avoiding litigation to determine what treatment you really desired or intended. In any event, it is time well spent.

Is an Advance Directive the same as a Do Not Resuscitate (DNR) order?

No, however an Advance Directive may include the instruction to withhold CPR and not initiate resuscitation measures. When one enters a healthcare environment, the medical staff will review and confirm the information from the Advance Directive with the individual's primary physician and he/she will issue a DNR order to the medical staff. The DNR order becomes a part of the physician's orders in the person's medical file, which serves as a communication tool for the medical team.

Can a DNR order be implemented without a terminal condition in a DMRDD facility?

No, not in a DMRDD contracted non-skilled nursing facility.

It is important to understand that a "do not resuscitate" order is compatible with maximal therapeutic efforts, short of resuscitation, and that the individual is entitled to receive vigorous support in all other therapeutic modalities, even though a "do not resuscitate" order may have been written for implementation in a skilled medical facility. The Department's role is to assure that the individual's level of functioning is not considered in the decision to issue or execute a "do not resuscitate" order. A non-hospital DNR order may be followed in a DMRDD facility when the individual is deemed terminal by the Division's definition.

What can I do if cardiopulmonary resuscitation would cause more harm than benefit?

If an individual's condition is not terminal but is such that cardiopulmonary resuscitation (CPR) would cause more harm than benefit to the individual and substantially compromise his or her well-being, the planning team and attending physician may determine what emergency medical care is needed. The attending physician should define the appropriate emergency medical care. Example: if the individual has a brittle bone disease/condition such that CPR could cause a breakage of bones thus puncturing the lungs, then CPR would not be advisable. That person may require an alternative method of resuscitation.

What is a Power of Attorney?

A power of attorney is a document by which you appoint a person to act as your agent. An agent is one who has authorization to act for another person. The person who appoints the agent is the principal; the agent is also called the attorney-in-fact. If you have appointed an agent by a power of attorney, acts of the agent within the authority spelled out in the power of attorney are legally binding on you, just as though you performed the acts yourself. The power of attorney can authorize the attorney-in-fact to perform a single act or a multitude of acts repeatedly.

Who May Be Appointed Under a Power of Attorney? (According to Missouri Bar)

The agent appointed by power of attorney may be any adult, and is often a close relative, lawyer or other trusted individual. The person appointed does not have to be a resident of the state of Missouri. However, under Missouri law, the following persons may **not** serve as attorney-in-fact:

1. No one connected with a facility licensed by the Missouri Department of Mental Health or Missouri Department of Social Services in which the principal resides, unless such person is closely related to the principal.
2. No full time judge and no clerk of court, unless closely related.
3. No one under 18, no person judicially determined to be incapacitated or disabled and no chronic substance abuser.
4. For a health care provider, no one who is the attending physician of the principal and no one who is connected with the health care facility in which the principal is a patient, unless such a person is closely related to the principal.

What is a "Durable" Power of Attorney?

Many people are unaware that an ordinary power of attorney is revoked, and the agent's power to act for the principal automatically stops, if the principal becomes incapacitated.

Under Missouri law, and the law of many other states, a power of attorney with proper wording may be made "durable." This means that the power of the agent to act on the principal's behalf continues despite the principal's incapacity, whether or not a court decrees the principal to be incapacitated.

Through a durable power of attorney, an agent may continue to act on your behalf even after you have had a stroke or other incapacitating illness or accident. If the power of attorney so provides, the agent can use your funds to pay your bills, can contract for nursing home services for your benefit and can make basic health care decisions for you.

An aging parent may wish to give a durable power of attorney to a responsible adult child so that the child can act on the parent's behalf and carry on routine matters in the event the parent is disabled or incapacitated. In many instances, this arrangement is far better than making the child the joint owner of the parent's bank accounts and other property and assets.

To create a durable power of attorney in Missouri, the title to the document must include the word "durable" and the document must state: "This is a durable power of attorney and the authority of my attorney-in-fact shall not terminate if I become disabled or incapacitated." In many other states, the document must state in substance that "this power of attorney shall not be affected by subsequent disability or incapacity."

It is possible to create a durable power of attorney so that it will only go into effect when the principal is incapacitated or when some other stipulated event or condition occurs. This is ordinarily called a springing durable power of attorney.

Revocation of Durable Power of Attorney

The death of the principal revokes even a durable power of attorney, except for a third person relying on the power of attorney who does not know of the death. Also, a durable power of attorney may be

revoked by the principal at any time, either orally or in writing. It is recommended that, when possible, the revocation be written.

Powers Granted by General Powers of Attorney

Under Missouri law before August, 1989, a valid power of attorney had to spell out in detail all of the authorizations granted to the agent. Under a new Missouri law adopted in August, 1989, it is possible to have a "general" power of attorney which authorizes the agent to act for the principal on every kind of subject or matter which may legally be handled through an agent, with certain specific exceptions mentioned below. However, it is still recommended that the power of attorney include as much detail as possible.

Powers Which Must Be Specifically Listed

In Missouri, certain powers must be specifically stated in the power of attorney in order for the attorney-in-fact to be authorized to perform such acts.

Those powers are:

To execute, amend or revoke any trust agreement;

1. To fund with the principal's assets any trust not created by the principal;
2. To make or revoke a gift or devise of property to or for the benefit of the principal.
3. To disclaim a gift or devise of property to or for the benefit of the principal;
4. To create or change survivorship interests in the principal's property or in property in which the principal may have interest;
5. To designate or change the designation of beneficiaries to receive any property, benefit or contract right on the principal's death;
6. To give consent to an autopsy or postmortem examination;
7. To make a gift of the principal's body parts under the Uniform Anatomical Gift Act;
8. To nominate a guardian or conservator for the principal;
9. To give consent to or prohibit any type of health care, medical care, treatment or procedure; or
10. To direct the withholding or withdrawal of artificially supplied nutrition or hydration.

Powers Which May Not Be Granted By a Power of Attorney

No power of attorney governed by the Missouri law may grant power to an agent to carry out any of the following actions for the principal:

1. To make, publish, declare, amend or revoke a will for the principal;
2. To make, execute, modify or revoke a living will declaration for the principal;
3. To require the principal, against his or her will, to take any action or to refrain from taking any action; or
4. To carry out any actions specifically forbidden by the principal while not under any disability or incapacity.

Must I Sign a Power, and if I Do, Will it Be Followed?

No person can be forced to sign a power of attorney, especially one for health care decisions, which cannot be required for admission to a hospital. Once created, your directions must be followed. If a physician or other health care provider declines to follow your instructions due to religious beliefs or moral convictions, such health care provider must transfer the care of the patient to another physician

or facility that will honor the patient's instructions. For this reason, it is always advisable to discuss these issues with your physician in advance of any hospitalization or extensive treatment.

Caution in Preparing and Granting Powers of Attorney

An effective durable power of attorney, and especially a springing durable power of attorney, needs to be very carefully worded and you should seek the assistance of a Missouri lawyer who practices in this area. Furthermore, you should use great care in the selection of your attorney-in-fact. Remember, you are trusting not only your property, but perhaps your life, to the person you appoint.

Living Wills and Other Advance Directives

What is a Living Will?

A living will is a brief declaration or statement that a person may make indicating their desire that certain medical treatment be either withheld or withdrawn under certain circumstances. The Missouri statute authorizing the creation of living wills specifies that the statement or declaration be in substantially the following form:

"I have the primary right to make my own decisions concerning treatment that might unduly prolong the dying process. By this declaration I express to my physician, family and friends my intent. If I should have a terminal condition it is my desire that my dying not be prolonged by administration of death-prolonging procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw medical procedures that merely prolong the dying process and are not necessary to my comfort or to alleviate pain. It is not my intent to authorize affirmative or deliberate acts or omissions to shorten my life, rather only to permit the natural process of dying."

How is a Living Will Made?

Any competent person 18 years of age or older can make a living will by signing and dating a statement similar to that shown above before two witnesses. These witnesses must be at least 18 years old, and should not be related to the person signing the declaration, a beneficiary of his or her estate or financially responsible for his or her medical care. The statement can be typed or handwritten. It is recommended that a living will or any other advance directives be considered and prepared in advance of any hospitalization or impending surgery it is not something anyone should feel pressured to decide in a short period of time, if that can be avoided.

Limitations of Living Wills

While most people have heard of living wills, many are unaware of the significant limitations of the living will as defined by Missouri statutes. The terms "death-prolonging procedure" and "terminal condition" are used in the statute to specify the circumstances to which a living will applies. The statute defines both of those terms as relating to a condition where death will occur within a short period of time whether or not certain treatment is provided. In other words, the patient will die shortly with or without artificial resuscitation, use of a ventilator, artificially supplied nutrition and hydration or other invasive surgical procedures. By definition, then, a living will only avoids treatment when death is imminent and the treatment is ineffective to avoid or significantly delay death. Furthermore, the statute prohibits a living will from withholding or withdrawing artificially supplied nutrition and hydration, which is sustenance supplied through a feeding tube or IV.

Alternatives to Living Wills

For patients who desire to give instructions for their health care which exceed the limitations of the living will statute, there is an alternative, commonly referred to as "advance directives." An advance directive is an instruction by a patient as to the withholding or withdrawing of certain medical treatment in advance of the patient suffering a condition which renders the patient unable to refuse such treatment. A competent patient always has the right to refuse treatment for him or herself or direct that such treatment be discontinued. Without an advance directive, once a patient becomes incapacitated, he or she may well lose that right. A living will is simply one type of advance directive. Recent court cases have made it clear that people have the right to make other types of advance directives which exceed the limitations of the living will statute. Those directives need to be "clear and convincing," and may include instructions to withhold or withdraw artificially supplied nutrition and hydration or other treatment or machinery which may maintain a patient in a persistent vegetative state. These expanded advance directives can be tailored to meet the needs and desires of each individual patient, and need not be in any standard form. For example, they can specify that certain procedures are to be used for a reasonable period of time and then discontinued if they do not prove to be effective. Generally, additional advance directives should be signed, dated and witnessed in the same manner as living wills.

What Should I do With My Living Will?

The most important part of having a living will or other advance directives after they are signed is to be certain that they are accessible. They should be kept close at hand, not in a safe deposit box, because they may be needed at a moment's notice. Many people travel with them. Some even keep them in their purse or billfold. At a minimum, it is recommended that you deliver a copy to your attending physician and at least make your close relatives aware that you have one. Giving a copy of your living will or other advance directives to your physician gives you an opportunity to discuss your desires and ask any questions you may have about any procedure and also to ask your physician if he or she will follow your directions. If you have appointed an attorney-in-fact to make health care decisions in case of your incapacity, he or she should have a copy. If you are hospitalized, a copy should go into your medical records. For these reasons, it is often wise to sign more than one copy of your living will or other advance directives.

Revoking a Living Will

Once made, a living will or other advance directives are easily revoked or cancelled. They can be revoked either orally or in writing. If possible, it is advisable to gather and destroy all copies of the advance directives if you desire to revoke them. By statute, health care providers are required to note a revocation of a living will in the medical records of the patient.

Durable Power of Attorney

If you have a durable power of attorney which appoints someone to make health care decisions for you, do you still need a living will or other advance directives? The answer is yes. Whether or not you have a power of attorney does not affect the need or desire for a living will or other advance directives. If you do not have a power of attorney, your advance directives will be very helpful to instruct your physician and the hospital as to the care you desire. If you do have a power of attorney,

your advance directives will give very important guidance to your attorney-in-fact as to how he or she should act. In fact, you may want to combine your power of attorney, your living will and your other advance directives into one document.

General Information on Hospice Organization:

What Is Hospice & Palliative Care

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Hospice focuses on caring, not curing and, in most cases; care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual's needs must be continually assessed and treatment options should be explored and evaluated in the context of the individual's values and symptoms. Palliative care, ideally, would segue into hospice care as the illness progresses.

How does hospice care work?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The team usually consists of:

- The patient's personal physician;
- Hospice physician (or medical director);
- Nurses;
- Home health aides;
- Social workers;
- Clergy or other counselors;
- Trained volunteers; and
- Speech, physical, and occupational therapists, if needed.

What services are provided?

Among its major responsibilities, the interdisciplinary hospice team:

- Manages the patient's pain and symptoms;
- Assists the patient with the emotional and psychosocial and spiritual aspects of dying;
- Provides needed drugs, medical supplies, and equipment;
- Coaches the family on how to care for the patient;
- Delivers special services like speech and physical therapy when needed;
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time; and
- Provides bereavement care and counseling to surviving family and friends.

Additional Resource:

<http://www.ago.mo.gov/publications/lifechoices/lifechoices.pdf>